

**MINUTES
of the
THIRD MEETING
of the
DISABILITIES CONCERNS SUBCOMMITTEE
of the
LEGISLATIVE HEALTH AND HUMAN SERVICES COMMITTEE**

**October 9, 2014
Hotel Albuquerque, Franciscan Room
Albuquerque**

The third meeting of the Disabilities Concerns Subcommittee of the Legislative Health and Human Services Committee was called to order by Representative Doreen Y. Gallegos, chair, on Thursday, October 9, 2014, at 10:28 a.m. at the Hotel Albuquerque in Albuquerque.

Present

Rep. Doreen Y. Gallegos, Chair
Sen. Nancy Rodriguez, Vice Chair
Sen. Linda M. Lopez
Rep. James Roger Madalena

Absent

Sen. Craig W. Brandt
Rep. Nora Espinoza

Advisory Members

Rep. Miguel P. Garcia
Rep. Edward C. Sandoval
Rep. Elizabeth "Liz" Thomson

Rep. Phillip M. Archuleta

Guest Legislators

Sen. Gerald Ortiz y Pino
Sen. Mary Kay Papen

Staff

Shawn Mathis, Staff Attorney, Legislative Council Service (LCS)
Michael Hely, Staff Attorney, LCS
Rebecca Griego, Records Officer, LCS
Nancy Ellis, LCS

Guests

The guest list is in the meeting file.

Handouts

All handouts and other written material are in the meeting file.

Thursday, October 9

Welcome and Introductions

Representative Gallegos welcomed subcommittee members, staff and members of the audience, many of whom are attending the three-day Southwest Conference on Disability being held concurrently at Hotel Albuquerque. It was noted that 2015 is the twenty-fifth anniversary of the federal Americans with Disabilities Act of 1990 (ADA) and the fiftieth anniversary of Medicaid.

Repeal of the Federal Marriage Penalty for Persons with Disabilities

Marilyn Martinez, advocate for the disabled, is an artist and long-time proponent of changing federal law so persons with disabilities do not lose half of their benefits by getting married. Ms. Martinez said she has been writing to New Mexico's congressional delegation since 2000, and she feels the time is right to make this effort again. She provided members with a copy of a 2007 memorial from the state legislature requesting federal action on this and information about the Supplemental Security Income (SSI) Restoration Act of 2014 (S.2089) that was introduced in the U.S. Senate last year and proposes to restore some, but not all, of the benefits to married persons who are disabled. Nat Dean, who has traumatic brain injury and is also an advocate for this change, provided a sample letter for subcommittee members, legislators and other interested persons requesting New Mexico's congressional delegates to urge removal of this federal penalty. Ms. Martinez said that SSI is the only federal assistance program to penalize individuals for marriage; neither the Temporary Assistance for Needy Families Program nor the Supplemental Nutrition Assistance Program has a similar penalty. The marriage penalty under SSI perpetuates the image of disabled persons not being expected to fully participate in society, she said.

Upon questioning, Ms. Martinez provided details of the current law, apparently based on the philosophy that two people can live more cheaply than one. Two disabled individuals can live together and each gets full benefits, but if they get married, their benefits are reduced 24.9 percent, and the amount of resources each can hold is reduced. If only one person in the marriage is disabled and receives SSI benefits, the penalty still applies, and individuals may lose their benefits altogether depending upon the couple's income and assets. A member commented on Ms. Martinez's extensive efforts on behalf of the disabled community, including hosting a public access television show about disability issues, and stated that this penalty helps keep people in poverty by preventing them from saving to buy a house or car, or for education or retirement. Another member made a motion to direct LCS staff to prepare letters to the Social Security Administration and other appropriate agencies and departments and urged that an effort be made to revisit the 2007 memorial. The motion was seconded and passed unanimously.

Provider Rates Increases

Anna Otero Hatanaka, executive director of the Association of Developmental Disabilities Community Providers, acknowledged that she has appeared multiple times this interim to testify on the need for provider rate increases, and she said she is extremely concerned

that disaster is looming; she is trying to provide education about the crumbling provider infrastructure. Some agencies are no longer providing certain services, others have laid off staff and some are closing their doors altogether. Recently, she and other advocates met with Keith Gardner, the governor's chief of staff, and provided a letter to the governor from the New Mexico Family Infant Toddler (FIT) Interagency Coordinating Council asking for rate increases to prevent many agencies from discontinuing FIT services (see handout).

Mark Johnson, chief executive officer (CEO) of Easter Seals/El Mirador, thanked members of the subcommittee for their advocacy, and he described his agency's 40-year history of providing community-based services in northern New Mexico. The rate structure of the developmental disability (DD) waiver program directly impacts the financial viability of his own organization, Mr. Johnson said. Direct care professionals have stringent hiring requirements — drug screens and criminal record and background checks — yet pay is low and turnover is high, often because of burnout. It is very difficult to find qualified staff willing to work with this population, he said, and the high turnover impacts compliance and quality improvement. Six organizations already have left the region because they could not maintain their agencies on current rates of reimbursement.

Rex Davidson, executive director of Las Cumbres Community Services, said his organization serves 6,000 square miles in northern New Mexico with a variety of support services. Las Cumbres is headquartered in Espanola, is the FIT provider in Rio Arriba County and provides behavioral health and other services in Los Alamos, Santa Fe and Espanola. It is very challenging to provide community-based services in rural areas, Mr. Davidson said, and now many organizations with boards of directors are having to make tough decisions on which programs to keep. His organization spent \$250,000 on travel last year, and the mileage paid to employees for home-based services is not reimbursed. He thanked legislators for the rate increase approved last year that his providers have not yet received; whether that increase will be enough to make a difference remains to be seen. Supported employment is being lost across the state, Mr. Davidson reported, because services cost more to provide than are reimbursed. Supported living also is not financially viable. Work force issues are much worse now than they were nine months ago because Centennial Care's four large managed care organizations (MCOs) offered many of his employees as much as 80 percent more than they were making with Las Cumbres, Mr. Davidson said, and it simply was not possible to compete. Audits are now conducted two to three times a year, and while they should be constructive, they are adversarial, he said. More agencies are going to be lost, and the situation is critical.

Gwendolyn Kiwanuka is director of adult services for LifeRoots, an Albuquerque nonprofit organization that provides services to children and adults with developmental, physical and behavioral disabilities. Inadequate reimbursement has forced her agency to cut back on supported employment, and LifeRoots providers also are still waiting for the rate increase promised in July. Agencies are expected to deliver quality services, but LifeRoots has not been able to give staff rate increases for the last five years, Ms. Kiwanuka said. She urged members to convince the state to establish appropriate rates.

Peggy O'Neill, CEO of Zia Therapy Center, Inc., in Alamogordo, told members that during the last fiscal year, four different DD waiver services lost significant amounts of revenue at her agency. The FIT Program lost \$102,000 and in previous years was staffed by personnel with over 20 years experience; now their most experienced provider has been with the center for just 18 months. They train providers, then they get hired away, Ms. O'Neill said. New Mexico has been at the top in quality for the FIT Program, but the state has been subsidizing it on the backs of providers, she asserted. Without immediate help, her company is going to be closing programs. Zia has been an important employer in the community, she said, and emergency funding is needed as soon as possible.

Ms. Hatanaka told subcommittee members that \$5 million is needed for the DD general fund program, \$5 million is needed for Medicaid DD waiver services and \$5 million is needed for the FIT Program.

On questioning, panel participants and subcommittee members discussed the following topics.

Status of the rate increases. Cathy Stevenson, director of the Developmental Disabilities Supports Division, Department of Health, who was recognized by the chair from the audience, said that the increased rates will be implemented by November 1 and will be retroactive to July 1, 2014. Delays are due to needed changes in codes with Medicaid and information technology issues with New Mexico's Medicaid computer system. Ms. Stevenson said her division is monitoring this delay daily. A member noted that if money is not in the proposed budget at the Legislative Finance Committee (LFC), rate increases will not get funded. Ms. Hatanaka said that her providers have been allotted 10 minutes to present to the LFC in late October. The chair provided a copy of a letter dated October 1, 2014 from the subcommittee to the LFC requesting additional time for service providers to present their urgent issues.

Why audits are increasing. Mr. Davidson said audits are conducted by the state, the MCOs, the attorney general, Xerox and OptumHealth. There are program audits, financial audits and Jackson compliance audits, he said, and their numbers have increased dramatically in the past two years. His company spends a lot of time and money on staff to handle these audits. Too many entities can request whatever they want for whatever time frame they desire, Mr. Johnson said. A subcommittee member asserted that multiple audits are a waste of taxpayer money and agency resources, while many issues that matter greatly are not getting the resources.

Status of Easter Seals/El Mirador fraud investigation. Mr. Johnson said the Human Services Department (HSD) re-referred Easter Seals/El Mirador's case back to the attorney general after it had been cleared of fraud because the HSD maintained that the wrong criteria had been used in the investigation. While Mr. Johnson was told it would take just a few weeks to clear it up, it has now been more than four months, and no one from the Office of the Attorney General has contacted Easter Seals/El Mirador. A member asked about funds that have been

withheld from Easter Seals/El Mirador for Medicaid services. The funds — \$650,000 for services that were delivered — are still being withheld, Mr. Johnson said, adding that to this day, there has been no disclosure of the allegations and no due process; his company has been waiting for 17 months.

Accounting of agency funds held in escrow by OptumHealth. The chair asked if there was anyone in the audience from OptumHealth or the HSD who could explain what is going on with that escrow account. Hearing no response, a member moved that a letter be sent to the HSD asking for a complete accounting from OptumHealth of all funds being held back from all 15 agencies and of any interest earned. The motion was seconded and approved unanimously.

2014 House Memorial 9 (HM 9) Status Report

Elizabeth Peterson, director of the Brain Injury Advisory Council, said that HM 9 directed the council to conduct a statewide concussion needs assessment for middle and high school athletes and for veterans to address concerns about people who have suffered concussions and not obtained proper diagnosis and treatment. Presenting with Ms. Peterson was Robert Thoma, Ph.D., associate professor in the Department of Psychiatry and Behavioral Sciences and the Center for Neuropsychological Services at the University of New Mexico (UNM) School of Medicine.

Dr. Thoma said a team already has been assembled to support this cutting-edge study, including participation from UNM's Brain and Behavioral Health Institute. The youth concussion study received human-subject approval in early fall, and now an awareness program is under way aimed at coaches, pediatricians, primary care providers and others, he said. A second study will involve the Veterans' Services Department in assessing veterans who suffer from traumatic brain injury and determining what resources are available to them. There is no funding for the veterans' study yet, Dr. Thoma said, but a team of UNM medical students has begun to gather information. Ms. Peterson emphasized that service gaps need to be identified for all New Mexico residents and a comprehensive system of treatment needs to be developed, especially in rural areas.

2014 House Memorial 87 (HM 87) Report

Susan Gray, chair, Governor's Commission on Disability (GCD), and Heather Stanton and Yvonne Dance, both of the Homeland Security and Emergency Management Department (HSEMD), provided reports on HM 87 (see handouts). This memorial requested the GCD to ensure that New Mexico's emergency operations plan (EOP) complies with Title II of the ADA and to identify barriers to compliance with or deficiencies in the plan. Ms. Gray referred to well-publicized problems with evacuations of people with disabilities after Hurricane Katrina in New Orleans and Hurricane Sandy in New York City, and she emphasized the state's legal obligation to provide these individuals with appropriate emergency evacuation plans.

Formal recommendations of the work group, presented by Ms. Stanton, included a revision of the EOP to include explicit language regarding compliance with Title II of the ADA;

incorporation of an accessible statewide emergency mass notification system into the EOP and emergency management, with a funded position at the HSEMD to manage this; and changes in state law to provide the HSEMD with the regulatory authority and personnel to adequately oversee ADA compliance of all current local emergency plans. Additionally, the work group advised the creation of a second task force to be charged with reviewing literature for the best evidence-based practice, an analysis of barriers and potential solutions, and the development of an inclusive ADA-compliant plan. This plan should include provisions for needs assessment guidance, technical support and training and individual preparedness and determine details and funding for the additional HSEMD position.

D In conclusion, Ms. Gray said, it is in the best interests of the state to take a proactive approach to planning for and including individuals with disabilities in emergency management and response. Not only is this the law, she said, but also the state bears considerable liability for its disabled residents in the event of a disaster.

During discussion following the presentation on HM 87, Anthony Alarid, access specialist with the GCD, described a long-standing issue at the State Capitol regarding restrooms. There is no women's restroom off the legislative house lounge, and female members and staff must walk to a different part of the building to access a restroom. Mr. Alarid presented plans to turn the existing men's restroom into a women's restroom and convert an existing unisex restroom into the men's restroom. The elimination of the unisex restroom requires a code variance; an alternative location for the required unisex restroom has been identified on the second floor and will allow greater public access. Mr. Alarid provided members with copies of the code variance request, floor plans and plans for funding of the new unisex restroom.

Update on *Waldrop v. New Mexico Human Services Department*

Jim Jackson, executive director of Disability Rights New Mexico (DRNM), introduced Jason Gordon, a staff attorney with DRNM who is working on litigation filed last January in federal court against the HSD regarding its provision of services under the DD waiver and its use of the Supports Intensity Scale (SIS) tool. In 2013, the HSD began using the SIS tool to determine support needs for every individual on the DD waiver, with each being assigned a letter group A through G. The budget for services is capped for each group with few exceptions, G being those with the most intense needs. This has resulted in fewer services than previously available to some in the A and B groups, Mr. Gordon explained, and his organization has received numerous complaints from consumers and treatment providers about the reduction in services. An interim agreement has been reached with the state, Mr. Gordon reported, so those individuals in groups A and B would not be forced to change their living situations or have their therapies reduced during the pendency of this litigation. A three-day hearing was held in August, and it is anticipated that a ruling may come by the end of the year.

T There are three major problems being addressed by this lawsuit, Mr. Jackson explained. The first of these is that the conduct of the SIS assessment is not sufficiently individualized as required by federal law when consumers are assigned to one of the large groups. Service

providers who attended SIS assessments have reported that their input was not taken into account. A second issue is that the SIS is purported to be one of many factors taken into account in determining service level needs, but it appears that the SIS is being used as the sole measure, Mr. Jackson said. The third issue involves due process violations; federal Medicaid law requires a fair hearing process, and this has not been working the way the law requires, Mr. Jackson asserted. A SIS evaluation takes two to three hours, but the evaluator is never brought to court during a fair hearing. Instead, the state brings in several HSD employees who testify in general terms, but who have never even met the consumer who was evaluated. Additionally, a budget has to be made and approved in order to be appealed, and there has been considerable confusion among caregivers and case managers about the appeal process. The DRNM asserts that the appeal process should have been promulgated as rules, and it is asking the court to restore benefits to consumers until the case is decided.

Mr. Jackson explained that the DRNM is not asking the court to set aside the SIS. The state has every right to choose an assessment tool, he said. What is being asked is for the state to comply with state and federal law in its assessment process. If a consumer loses services, that individual must be allowed to dispute the decision, and this has not been happening. In multiple DRNM lawsuits brought in district court, all were decided in favor of DD waiver participants, he said.

On questioning by subcommittee members, Mr. Jackson described the Fair Hearings Bureau within the HSD, which makes the determination, with the director of the Medical Assistance Division (MAD) of the HSD making the final decision. Generally, SIS assignment cases pursued on behalf of consumers by the DRNM in administrative hearings (approximately 15) have been decided in favor of the HSD, he said. A member noted that in some states, the SIS is being utilized to determine when more services are needed instead of as a tool to dismantle services. It is constituents who are in limbo, the member asserted, adding that perhaps New Mexico should go back to the drawing board.

Proposed Amendment to the State Use Act

Scott Scanland, lobbyist for San Juan College and the City of Farmington, distributed a copy of the proposed legislation to members (see handout). Senator William E. Sharer's bill would add one percent to the five percent advantage already established in the State Use Act to create a preference for certain businesses owned by or operated in the interest of persons with disabilities. It also would require a formal request for proposals and competitive bid process that would render the system one of "preference" instead of an automatic set-aside with no competition. This legislation would continue the New Mexico Council for Purchasing from Persons with Disabilities' role in the process but would eliminate the exemption from the provisions of the Procurement Code.

Senator Sharer answered members' questions about the State Use Act and changes that he is proposing. The state purchasing agent is the head of the council, and its membership is composed of more than just state employees; it also includes persons with disabilities who own a

business and other persons with disabilities. A member commented that persons with disabilities can be mainstreamed and should compete just like anyone else, but agreed that it is appropriate to give a slight preference.

Minutes Approved

Minutes from the September 9, 2014 meeting were unanimously approved, with the correction that Senator Lopez was present, not absent as listed.

Public Comment

Sheila Johnson said she came to the meeting today to ask for help with her daughter's service dog that is in need of medical care. She pointed out that Medicaid will pay up to \$20,000 for a specialized wheelchair, but her request for reimbursement of more than \$10,000 for the service dog has been denied, even though the dog's services have been "prescribed". Ms. Johnson said she has been doing fundraisers and has contacted the American Service Dogs and rescue at Petco and other organizations for help, but she does not know where else to turn. A subcommittee member agreed that there is a need to help pay for these dogs and suggested that this concern be brought to the MAD.

Danny Palma said he has a child on the DD waiver wait list and reported that it is a myth that New Mexico's waiver is among the most expensive in the country. Mr. Palma provided a spreadsheet with detailed information about this (see handout). However, New Mexico's wait list is 900 percent longer than the average state's wait list. There is never going to be enough capacity, Mr. Palma said, but that should not be a reason to delay funds for getting more people off of the wait list and into services.

Jim Parker spoke about the importance of access to medical marijuana, with more people able to use it for pain, muscle spasms and sleep disorders, among others. Mr. Parker said he is tired of the negative side effects from using pharmaceuticals and that he intends to apply for a prescription for medical marijuana. It is unfortunate that insurance will not cover this remedy, Mr. Parker said, and he urged legislators to look into this.

Ms. Stanton, who testified earlier on HM 87, said she is personally passionate about the importance of including the disabled in emergency planning. She pointed out the class action lawsuit against former Mayor Michael Bloomberg in New York City for ad hoc accommodations during Hurricane Sandy is driving the urgency of action in New Mexico, stating that advance planning is in the best interests of all residents.

Charles Powell said he was speaking on behalf of a woman who is blind and uses a service dog. She has suffered many indignities at the hands of private businesses and public employees, he said. The root of the problem is that people who serve the public do not know what the law requires of them, Mr. Powell said. Private businesses and public agencies should require their employees to be aware of ADA requirements so that those with disabilities do not have to suffer indignities.

June Montoya has a 27-year-old daughter on the DD waiver who is looking for a more independent living situation, but she does not find a lot of options. She wants to live with roommates of her own choosing who are closer to her in age. Supported living situations are limited, Ms. Montoya said, and she is hoping to find more options that will work for her daughter rather than options determined by a provider agency.

Ellen Pinnes, an attorney with DRNM, said she wants to follow up on the State Use Act discussion, which is a complex issue. One of the shortcomings of the act is that it does not promote integrated employment. Ms. Pinnes said she would be happy to work with any group seeking to promote everyday employment rather than having a totally separate system.

Adjournment

There being no further business, the subcommittee adjourned at 4:30 p.m.